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An Elephant in the Consultation Room?: Configuring Down Syndrome in British Antenatal Care

This article is based on an ethnographic study of prenatal screening for Down syndrome in two British healthcare institutions. Drawing on observations of everyday hospital life and interviews with healthcare professionals, I identify how a discussion of Down syndrome is avoided within prenatal screening consultations. This relative silence is created and upheld owing to three observations: 1) the British public is interpreted as “knowing” what Down syndrome is; 2) the organization of care dictates that the condition is not classified as important enough to justify an explanation within consultations; 3) professionals frequently admit to holding minimal knowledge of Down syndrome. This absence, together with the condition being categorized as a “risk” or “problem,” helps produce and uphold its status as a negative pregnancy outcome. I conclude by highlighting the contributions that this article has for anthropologically exploring how ideas around disability intersect with the proliferation of reproductive technologies.

Introduction

It is almost 150 years since John Langdon Down first described what is now known as Down syndrome (or Trisomy 21). Down syndrome is one of the most common chromosomal conditions in the world and symptoms can include learning difficulties, reduced muscle tone, shortened limbs, restricted physical growth, a flat profile of the face, and a large protruding tongue (NHS FASP 2012). Although a common feature of Down syndrome is the variability and inconsistency of its manifestation, the condition is often “compatible with life” or “not lethal” (Ivry 2009), meaning individuals are likely to survive childbirth. Indeed, people with the condition are now leading longer, healthier lives and can survive beyond sixty years today (CARIS 2012).

In 2011, approximately 74% (N=542,312) of all expectant mothers in England and Wales (no statistics for Scotland were found) opted to be screened for Down syndrome (NHS FASP 2012), although statistics vary significantly between countries (Vassy et al. 2014). Additionally, in 2012 in England and Wales, of the 1,259 prenatal diagnoses of Down syndrome, 90% were terminated (N=983), 7% were live births (N=76), and 3% were natural miscarriages or stillbirths (N=34), though the outcome of 166 prenatal diagnoses is unknown (Morris and Springett 2014). From the first report in 1989 until 2012, the annual rates for termination in England and Wales have ranged from 88% to

94%. Since Down syndrome has taken such a central position in British reproductive politics, it is ripe for an anthropological analysis to establish the contours, complexities, and contradictions emerging in antenatal care.

In this article, I unpack how Down syndrome is discussed within prenatal screening consultations. Many authors capture the problematic relationship between disability and reproductive technologies (Ginsburg and Rapp 1995, 2013; Ivry 2006; Landsman 2009; Parens and Asch 2000; Rapp 1999, 2000; Rothman 1994; Shakespeare 1999; Vailly 2014). However, many of these accounts are guilty of two charges. First, they often rely on scholarly speculation or interview data alone (Asch 1999; Remennick 2006). Whilst the substance and contribution of such accounts cannot be discounted, attending to the mundane interactions of the antenatal clinic reveals important contributions regarding how Down syndrome is constructed in medical practice. Second, disability and Down syndrome specifically are commonly framed as universal categories. Davis (1995:xv) identifies the totalizing tag of "disability" as an unstable category denying the variability of the body; "the category 'disability' begins to break down when one scrutinizes who make up the disabled." The same can be said for Down syndrome, a complex and variable condition. Rather than utilizing a universal term unfairly and inappropriately pigeonholing Down syndrome and creating rigid categories of existence, I recognize it as a critical site worthy of independent scholarly attention owing to its complexity and notoriety in antenatal worlds.

In what follows, I initially provide a brief outline of my study. Turning attention to fieldwork, I identify how Down syndrome is rarely, if explicitly, discussed during screening consultations. This relative silence is upheld owing to three observations: 1) the wider public is framed as "knowing" what Down syndrome is; 2) the organization of care dictates that the condition is not classified as important enough to explain in consultations; 3) professionals regularly admit to having minimal knowledge of Down syndrome. Absent yet present, Down syndrome is subsequently constructed within universalizing discourses of "risk," "problem," and "abnormality" which, perhaps inadvertently, fashion and sustain a negative outlook, as well as mask the variability and complexity, of the condition. Answering Han's (2013) call for attending to the mundane aspects of pregnancy, I present an analysis of the quotidian, of a routine medical procedure as opposed to new reproductive technologies (Rapp 2000), and suggest how unpacking the taken-for-granted interactions of everyday clinical life, in the tradition of Erving Goffman (1959; 1963) and Harold Garfinkel (1967), reveals new insights for medical anthropology and the anthropology of reproduction.

Setting and methods

In Britain, expectant parents are routinely offered screening for Down syndrome. During my fieldwork at two healthcare institutions – Freymarsh (NHS hospital) and Springtown (privately-funded fertility clinic) – two methods were used for screening: 1) serum screening (Freymarsh); 2) a nuchal translucency¹ ultrasound scan combined with serum screening (Springtown). Irrespective of the screening method undertaken, expectant parents are provided with a "risk factor," a numerical variable establishing the odds of a fetus having the condition. This is calculated using computer software which takes into account a number of maternal factors including age, weight, ethnicity, gestation, number of fetuses, pregnancy history, assisted conception, and smoking, together with the size of the nuchal translucency if an ultrasound scan is undertaken. Expectant parents are subsequently placed in

a “lower risk” or “higher risk” category. In the two antenatal clinics observed, the cut-off point for this categorization was 1:150 (a 1 in 150 risk of a fetus having Down syndrome). If expectant parents receive a risk factor above 1:150 (e.g. 1:250), they are categorized as lower risk and offered no further treatment other than an ultrasound scan at twenty weeks to check for potential problems (“anomaly scan”). In contrast, if expectant parents receive a risk factor below 1:150 (e.g. 1:100), they are categorized as higher risk and offered an amniocentesis or CVS (chorionic villus sampling) which confirms or refutes a suspected diagnosis. Although providing a diagnosis, possible complications of diagnostic testing include causing anxiety and a 1-2% risk of miscarriage (NHS Choices 2014). Expectant parents with a diagnosis of Down syndrome receive counseling before deciding whether to continue or terminate a pregnancy. The primary objective of screening is to identify expectant mothers in whom a risk factor is deemed high enough to warrant offering invasive diagnostic testing.

Data presented in this article are drawn from an ethnographic study taking place in two healthcare institutions. My research initially intended to unpack why scientific and medical communities, together with expectant parents, are so invested in prenatally detecting Down syndrome, a practice constituting a taken-for-granted component of British antenatal care. Around one year was spent observing each institution, paying attention to the routines, deviations, discourses, practices of division, and accounts in each setting. As with most ethnographic endeavors, I was guided by an interest in producing an in-depth evaluation of a research site and the lives of individuals within it. The ethnography took me into the many worlds which screening for Down syndrome permeates: antenatal departments, laboratories, homes, administrative offices, and so on. However, the majority of my fieldwork was spent in the antenatal departments of Freymarsh and Springtown. In this article, fieldnotes and sixteen interviews with professionals are drawn upon to make my claims.

Fieldnotes were recorded on site and typed up after leaving the field. Interviews were audio-recorded and ranged from thirty minutes to over two hours in length. Material was analyzed using “situational analyses” (Clarke 2003), a renovation of grounded theory in which all the key elements of the situation, the interrelations, the social worlds in which these are embedded, and the discursive positions taken by people were the focus of my analysis. Material was subsequently grouped together to establish dis/connections in observations and the accounts of participants. This was read alongside literature, allowing for an inductive approach, until intricacies and relationships were identified. Ethical approval was granted by NHS and University research ethics committees.

An elephant in the consultation room?²

Down syndrome screening is delivered by midwives at Freymarsh and sonographers at Springtown. In Freymarsh, midwives invite expectant parents into a room prior to screening (around sixteen weeks gestation). They highlight and reiterate the details of screening whilst expectant parents are offered an opportunity to ask questions and opt in/out of the procedure. In Springtown, no such consultation exists prior to undertaking a nuchal translucency scan. Instead, the procedure is described during the scan whilst the sonographer navigates the transducer around the expectant mother’s abdomen (approximately twelve to fourteen weeks gestation). If expectant parents receive a “higher-risk” result following screening (within ten days of the initial procedure), they are offered immediate counseling by a professional in which the result is discussed, a leaflet is distributed (the leaflet contains

information about diagnostic testing and Down syndrome), and diagnostic testing is offered. If expectant parents refuse testing, they receive no further treatment. If expectant parents accept testing, they return to hospital for the test usually a few days after counseling. Following the test, results are analyzed in a cytogenetics laboratory and full results are returned to expectant parents within a period of two weeks. If a diagnosis is established, expectant parents must decide whether to continue or terminate a pregnancy. This article exclusively draws on data from consultations in which screening is discussed or where a higher-risk result for Down syndrome is explained to expectant parents.

In most Freymarsh and Springtown consultations in which screening is discussed, Down syndrome is seldom addressed in explicit detail; at most, the condition is cited without further clarification. The following fieldnotes are taken from a nuchal translucency scan between Esther (sonographer) and Mr. and Mrs. Jones (expectant parents):

Esther: So here's your baby. You can see the heart beating away there. Little one's hiccupping as well [Mr. Jones and Mrs. Jones laugh].

Mrs. Jones: Maybe it's that sausage and chips I just had! [All laugh].

Esther: So we measure the nuchal translucency which is the pad of fluid at the back of baby's neck. When it's enlarged, it increases the risk of baby having a chromosomal abnormality. We do the measurement in combination with your blood-work so you will have some bloods done today. So the nuchal translucency and your age and your biochemical bloods and the length of the baby will give you a definite risk of three chromosomal abnormalities. We only screen for three, one of which is Down [syndrome] which I'm sure you know but also we look at Patau [syndrome] and Edward's [syndrome]³. I don't know if you've seen about these on the internet but they're three of the most common, two of the most lethal. So during this screening, you'll be placed in either the lower risk or higher risk bracket and if you're higher risk, you're advised to have an amniocentesis. Oh God you've got a wriggly one in here!

Mrs. Jones: It looks like it's doing the splits [laughing].

Esther: Yes, baby's doing a dance! We like the nuchal translucency to measure less than 3mm and your measurements are all under 3mm which is all great really.

Humor is littered throughout the encounter; Mr. Jones and Mrs. Jones are amused by the hiccupping which is ascribed to pre-scan behaviors (eating) and Mrs. Jones frames the fetus' movement as replicating the splits, whilst Esther describes this movement as a dance routine. This collaborative work between Esther and the Jones', essential to making the imagery on the ultrasound monitor personally and socially meaningful, reflects the intricate shifts between threat and thrill, that is, the (clinical) information communicated around screening practices and the (non-clinical) performances of sonographers, expectant parents, and fetuses. The threat involves divulging details of nuchal translucencies, chromosomal difference, and diagnostic testing. The thrill, in contrast, reconstructs the ultrasound scan as an entertaining experience for expectant parents.

But what happens to Down syndrome here? Throughout the consultation, whilst the condition is cited, no further details on Down syndrome are tendered by Esther nor solicited by the Jones'. Assumptions appear to govern proceedings; Down syndrome is shaped as something which the Jones'

should “know.” Interestingly, Esther describes the three syndromes screened for – Down syndrome, Edward’s syndrome, and Patau syndrome – as “chromosomal abnormalities” and as “three of the most common, two of the most lethal.” Esther refrains from clarifying which syndromes are lethal but rather relies on Mr. and Mrs. Jones calling upon tacit assumptions regarding which conditions are lethal and which condition is not. Similar to Garfinkel’s (1967) *et cetera* principal whereby people expect others to understand situations based on personal knowledge, Down syndrome is framed as a taken-for-granted category requiring no further elucidation regarding symptoms, prognosis, and the “social realities” (Rapp 1988:150) of the child who might have the condition.

Here, Down syndrome shares similarities to Latour’s (1999:304) “black box,” a metaphor referring to the way in which “scientific and technical work is made invisible by its own success.” In an analysis of how scientific knowledge is made durable, Latour (1991) suggests that such work is only defined by its function; the complexity of a given system’s internal workings is redundant providing it continues to serve its primary purpose and allows people to proceed in their daily activities. Its output, thus, retains the status of truth.

Whilst Latour’s description refers to how scientific facts are established, I suggest how the medical category of Down syndrome (as a “fact”) is established within screening practices. It becomes a curious black box, a “known” entity remaining unopened and shrouded. It is an elephant in the consultation room, with the midwife/sonographer not providing, and expectant parents not seeking or questioning, information around the condition. Much like Latour, I now turn my focus to unpacking how the black box of Down syndrome is solidified and made opaque, who is involved in this, what affects this has, and why this is significant when reflecting on the politics of reproductive care.

Accounting for absence

So why is Down syndrome absent during consultations? I identify three distinct yet intertwining reasons which shape this silence: 1) the familiarity of Down syndrome; 2) the organization of care; 3) the limited knowledge of professionals. I expand on each of these below.

The familiarity of Down syndrome

As alluded to in the extract between Esther and Mr. and Mrs. Jones, Down syndrome constitutes a taken-for-granted category which is recognizable to expectant parents. Several professionals suggest that the general public, at large, “know about” Down syndrome. However, they claim that this knowledge is limited to the obvious anatomical features, or “face” (Latimer 2013), of the condition. During an interview, Amy (midwife) explains:

I don’t think expectant parents understand Down syndrome much unless they have a family member or a friend who has a Down syndrome person in the family. But I think they know what a Down syndrome person looks like. They don’t always know a Down syndrome person can live until they’re sixty-five and seventy and they can live a relatively normal life in the sense that they get up in the morning, eat and dress, and that.

Similarly, Rita (midwife) suggests that expectant parents often convey their knowledge of Down syndrome by stating that people with the condition “look that way,” translating to the distinctive facial features caused by the presence of an extra chromosome. Susan and Maggie (midwives), among others, credit such awareness of the Down syndrome “face” to the familiar presence of people with the condition in British society. In an interview, Camilla acknowledges this familiarity when identifying the difficulties of communicating information to non-British expectant parents:

You get often women from other countries that don't speak English as a first language and maybe don't really understand what a baby with Down syndrome is because of language barriers and cultural differences. Whether they really understand what we're asking of them or what we're trying to explain in consultations, I'm not convinced. Some people do say 'I don't know what a Down syndrome baby is.' And you think, gosh, really [laughs]?

Rapp (1988, 2000) highlights how some non-US patients had no recognition of Down syndrome and how English-speaking communities generally held some knowledge of the condition. She suggests that local metaphors of pregnancy, birth, and parenthood do not easily translate “into the realm of medical discourse” (2000:81). During consultations, my own observations reveal that as well as obvious language barriers inhibiting interaction (this was more likely to occur in Freymarsh which served a larger non-British population), Down syndrome was, in turn, rarely explicated in any detail. Lois (midwife) suggests “it helps to know about Down syndrome as this would affect whether [expectant parents] have the screening or not,” with healthcare professionals often accusing expectant parents of not holding extensive knowledge of the condition excepting facial features. So why are no further details tendered?

In the clinic, the (aesthetic) familiarity of Down syndrome hinders a broad discussion of the symptoms, prognosis, and “social realities” of the condition. In addition, this avoidance emerges on account of expectant parents and professionals not wanting to consider it as a possibility. During an interview, Lisa (sonographer) suggests this is because despite its compatibility with life, Down syndrome is largely understood in negative terms:

I think [expectant parents] probably see [Down syndrome] as very negative by and large. I don't think they know how much support they would get or if they're told what life would be like if they're given the diagnosis of a Down syndrome baby. How much they're told will influence them whether they'd keep the pregnancy or not.

Whilst Lisa's contentions (Down syndrome is seen as “very negative by and large”) relate to terminating or continuing a pregnancy following a diagnosis, her claims are appropriate for considering how Down syndrome is configured in the early stages of antenatal care. The following fieldnotes were taken in the Springtown office where expectant parents can book ultrasound scans:

[Dominique, Juliana, and Hannah (administrative professionals) discuss the nuchal translucency scan].

Gareth: Do you think expectant parents having the nuchal translucency scan know much about Down syndrome?

Dominique: Not really. I think they know about the facial features.

Hannah: I don't think they want to know.

Dominique: It's not fully entered their heads.

Juliana: And they know about them being retarded.

Dominique: I don't think they know because it's such a broad spectrum of how they are affected too.

Hannah: Unless they know of someone in the family.

Juliana: We get more questions about Patau syndrome and Edward's syndrome. With these syndromes, they ask things like 'what are they?' Because they aren't as well known so we tell them about that and that's it really. We bracket it in with Down syndrome.

Hannah describes how expectant parents do not hold extensive knowledge of Down syndrome since "I don't think they want to know." Thompson (2013) shows how silence can act as a barrier against stigma or shame; interactional processes work around and mask difficult or taboo subjects. Similarly, during screening consultations, the imagined damage caused by the potential presence of a fetus with Down syndrome, as a future deviant body, initiates reluctance from expectant parents and midwives/sonographers to openly thrash out the nuts and bolts of the condition. This silence may also be interpreted as professionals attempting to reduce expectant parents' anxiety. In the case of screening, there is a tension between providing information and avoiding unnecessary anxiety for expectant parents. Thus, the topic of Down syndrome may be discouraged due to a sense of "jinx," that is, by naming the threat, it somehow becomes more likely to happen. In addition, professionals may not discuss Down syndrome in any great detail since they have little to offer other than a description of the variability and unpredictability of expression (professionals' knowledge is discussed later). This may be true not only for Down syndrome but for other conditions as well, highlighting the nature of discomfort in the face of ambivalence.

Nonetheless, Down syndrome seemingly amounts to what Taussig (1999:7) describes as a "public secret," namely the ideas of shared knowledge lodged in the imaginary of a particular society which are rarely described or openly acknowledged. Symbolically invisible and at its core banal, public secrets become a powerful social glue and social knowledge of "knowing what not to know" (1999:6). Notably, Taussig focuses primarily on the defacement of public secrets. During the consultations I observed, Down syndrome was not revealed as a public secret but rather remained a public secret, that is, a hidden and undisturbed category rarely unmasked. Here, the condition becomes significant by its absence, at the crossroads between the unmentioned and unmentionable. In sum, the condition is downgraded through its silence; it is in its familiarity (as a negative outcome) that Down syndrome becomes invisible.

The organization of care

A second reason why Down syndrome remains absent is that the organization of care hinders interactions between expectant parents and professionals. This is particularly evident in Freymarsh

where a checklist is used to govern clinical practice. The checklist includes eleven "key points to discuss," in Camilla's (midwife) words, during a consultation:

[After a consultation, Camilla fills in the checklist. The first side of the form asks for details such as scan date, ethnic origin, and weight. The second side contains a list of 11 points marked "Information Given" which must be clarified during consultations:

1. Gestation at the time of test
2. Have you had any other screening test for Down syndrome?
3. A low chance result $\geq 1:151$
4. Low chance does not mean no chance
5. Low chance result will be sent by letter within 10 working days
6. The low chance letter will not state the risk ratio
7. A high chance result $\leq 1:150$
8. High chance screening result will be provided within 5 working days
9. An appointment will be offered within 24 hours of contact to discuss a high chance result
10. Have you considered the amniocentesis test that will be offered following a high chance result?
11. If you accept an amniocentesis diagnostic test an appointment will be offered as soon as possible following a recall].

Camilla claims that "in order to cover our backs," midwives follow such rationalized stipulations to accomplish appropriate care. Martha (Freymarsh midwife) draws attention to the checklist's value:

It makes sure we're all practicing to the same standard so that one midwife doesn't go in and just skip through it. It standardizes practice. With other things you can't be all the same but with screening for Down syndrome, what we say should be standardized before the screening is done.

Lois (midwife) similarly explains that many aspects of antenatal care are reduced to "tick boxing, initialing, and that's it," similarly citing this as a positive development in the "streamlining" of tasks so there is "not too much paperwork." Midwives dutifully follow the checklist with the intention of providing "informed" choice without their own intervention. The neutral stance toward screening and testing assumed by professionals has been clearly stated as a principle for decades, meaning professionals in Britain allocate decision-making to supposedly rational and responsible expectant parents. The rationalization of their practice represents an effort to avoid any bias/morality; it consequently reduces care to providing "factually correct medical information" (Bosk 1992:19) specified on a checklist establishing the topics worthy of further exposition. The checklist used during Down syndrome screening consultations, thus, provides a welcome addition to the clinic since it specifies the important data requiring explication. This reflects the routinization and rationalization of care/screening practices. Press and Browner (1997) argue that the relatively banal way in which prenatal screening is presented leads to it becoming a routine procedure among other treatment practices. This relates to Down syndrome screening, in Freymarsh particularly, being offered alongside screening for other conditions or diseases such as rubella, HIV, syphilis, rhesus disease, sickle cell, thalassemia, and hepatitis B/C.

Returning to the checklist, a conversation about Down syndrome does not constitute one of the “key points to discuss” in a consultation. With care increasingly structured on rational grounds in the pursuit of efficiency, the rationalized stipulations introduced by organizational cultures determine what information is necessary for sharing with expectant parents. Although the checklist is exclusive to Freymarsh, the absence of Down syndrome during consultations in Springtown can also be attributed to an extensive deliberation of the condition being seen as non-essential. Operating within strict time constraints, midwives and sonographers condense information and only provide details deemed significant for expectant parents. Their conduct is shaped by wider organizational cultures which lead to Down syndrome being avoided and rendered absent, thus contributing to making the condition one of Taussig’s (1999) “public secrets”.

The limited knowledge of professionals

A third reason for the absence of Down syndrome corresponds to midwives and sonographers commonly admitting to lacking extensive knowledge of the condition. Whilst professionals do have some knowledge of the condition and likely symptoms, translating detailed knowledge to expectant parents is not always possible. When asked about her knowledge of Down syndrome, Sophie (sonographer) answers:

I must admit we haven’t particularly been taught a lot about it. I know a lot about testing for it but I don’t know a huge amount about the actual condition. I think it goes back if you know somebody with it and we’re taught things like the statistics, like 25% of them can have cardiac problems. But you’re not particularly taught about that when you do training and stuff.

Sophie credits her limited knowledge of Down syndrome with a lack of training and suggests her familiarity with it extends exclusively to screening practices and statistics (“25% of them can have cardiac problems”). According to several sources, however, the number of people with Down syndrome who have cardiac issues is closer to 50% (NHS FASP 2013). This reflects research suggesting that some professionals hold limited – if not outmoded – knowledge of the condition and have little direct contact during medical training with people who have developmental impairments (Skotko 2005). During a conversation, Rita (midwife) draws attention to the difficulties of describing a condition without great knowledge of it:

Even if you get a result that means expectant parents will be referred elsewhere, you’re the initial person to see them. Sometimes I find that a bit difficult because they start asking you questions and I cannot always answer them because I’m not specialized in that area. So I feel a bit bad then saying I’m not really the best person to speak to but I will get someone to speak to you.

Notably, Down syndrome is explained in more detail once a diagnosis is suspected and a higher risk result must be described to expectant parents in another consultation (to repeat, this follows the initial screening consultation and involves asking expectant parents if they want diagnostic testing). However, similar to initial screening consultations, the majority of such encounters are conducted by

midwives (Springtown sonographers bequeath this responsibility to a midwife) who frequently claim they have a limited knowledge of Down syndrome. During a consultation in which Mr. and Mrs. Knight (expectant parents) are told they have a higher risk of Down syndrome, for instance, Eve and Amy (midwives) describe what happens after diagnostic testing:

Eve: If the baby is diagnosed with Down syndrome, you can wait till your full karyotype is in to see whether it's mild or severe.

Mr. Knight: What is severe then?

Eve: I couldn't tell you that. Not now anyway.

Mrs. Knight: I think what my husband is asking is what would mild be?

Eve: Well a number of people with Down syndrome can go on to live till sixty years old, and [Eve seems unsure and pauses].

Amy: Yes, they can sometimes have learning difficulties. But if mild, they can appear quite normal.

Eve: Yes. They can have a similar IQ level to other children. They can live good lives, some can live independently. [Eve pauses again] It depends really.

Mr. Knight: I do have another different question: where does Down syndrome start?

Mrs. Knight: Where it's from?

Eve: It's an extra chromosome. That chromosome will be placed somewhere in the genes. We're not sure why it happens.

Mr. Knight: I read it was when the cells were divided in the chromosomes.

Amy: It's a chromosomal thing, yes. It's not genetic.

Mrs. Knight: [Turning to Mr. Knight] There's nothing we can do about it, it's not one of us.

Eve: Yes it's not a genetic thing.

Amy: Yes.

Eve: It's a chromosomal thing.

During such encounters, professionals discuss several issues with expectant parents including the meaning of risk factors, the benefits/risks of diagnostic testing, and possible outcomes if a diagnosis is established (continuing/terminating a pregnancy). This information is repeated in leaflets distributed to expectant parents at the end of the procedure. If they decide to pursue diagnostic testing, more leaflets are provided during this consultation about amniocentesis/CVS before undertaking the procedure. A higher risk result commonly causes expectant parents to ask further questions about diagnostic testing and risk factors in a consultation. Throughout this encounter, Mr. and Mrs. Knight ask questions regarding Down syndrome, one of which surrounds its causes. Yet, in most consultations of this nature, a discussion of the condition rarely extends beyond midwives or other professionals offering expectant parents a leaflet.

In Springtown, however, the written information provided to parents following a higher-risk result does not refer to Down syndrome; it is limited to information on amniocentesis, its risks, blood group types, what parents should do before and after the test, and when a result will be received. In contrast, the Freymarsh leaflet does offer further details on Down syndrome, specifically how it is a "lifelong condition which will result in some degree of learning disability". It also highlights how the cause of Down syndrome is unclear ("it is not known what makes this happen"), the common symptoms and

prognosis of the condition (“slanted eyes”; “looser muscles and joints than other babies”; “children usually develop and learn more slowly than other children”; “they may have some medical problems that need special attention and treatments”), and existing support services for parents. This description is balanced with more positive discourse relating to early prognosis (“most children will learn to walk and talk [...] go to mainstream schools and learn to read and write”) and later life (“most children and adults can lead healthy lives”; “adults can live partly-independent lives, choosing their friends and partners and working or contributing to society in other ways”). This contradicts the claims of Bryant et al. (2001) who argue that leaflets for Down syndrome screening often contain false, misleading, and inconsistent information on the condition. Even so, a familiar criticism among professionals in Freymarsh and Springtown is that expectant parents rarely read the literature. If true, the absence of Down syndrome in antenatal encounters becomes even more significant.

In the uncharacteristic case above with Eve, Amy and the Knight’s, whereby the expectant parents solicit details from professionals in a manner which opens the black box/unmasks the elephant in the room, Eve and Amy - particularly Eve - seem unsure about the condition and provide vague and incorrect information (despite, one may observe, this information being readily accessible in antenatal leaflets at the clinic). Here, there is a lack of knowledge of Down syndrome as “not genetic” (although Mr. and Mrs. Knight correctly interpret this term as signifying hereditariness⁴) and of people with the condition as “sometimes” having learning difficulties (people with the condition will always have cognitive impairment, although its severity and meaning is open to variation and interpretation). In addition, Eve’s claim that “you can wait till your full karyotype is in to see whether [the diagnosis is] mild or severe” is erroneous, namely since the severity of Down syndrome cannot be predicted on the basis of karyotyping.

Even on rare occasions where information on Down syndrome is shared or solicited during consultations, the finer details of symptoms, prognosis, and future prospects (physiological and social) are vague, incorrect, or excluded entirely. My intentions are not to humiliate or chastise professionals for their flawed knowledge regarding Down syndrome. Rather, I argue that one reason for this is that in Springtown and Freymarsh, screening is relegated down the medical hierarchy. Doctors and consultants in clinical medicine are specifically trained to manage cases such as Down syndrome and other genetic conditions, yet do not participate in screening practices. Instead, the task is collected by midwives and sonographers, that is, professionals with – as frequently and openly professed – limited knowledge of the condition. This identifies possible future training needs for professionals.

However, one may also consider this interpretation as a useful excuse. Professionals do not necessarily view a lack of knowledge about Down syndrome, despite its wide availability, as a deficit in performing clinical duties. Indeed, professionals are often not aware of current available services for, or the life-span or later-life health issues of, people with the condition, all of which narrow the context in which a response to a positive diagnosis will be made. Although training/internships are likely to remediate this knowledge deficiency, they are not pursued. As such, the absence of Down syndrome becomes a natural and enduring condition. Nonetheless, since neither party shares nor appeals for further information on the condition during most consultations, a negative depiction of Down syndrome – highlighted by professionals often suggesting that public attitudes toward the condition are largely negative – remains intact. The importance of some knowledge about Down syndrome for informed reproductive decision-making is emphasised by professionals in this study (criticising

expectant parents for not knowing what Down syndrome is) and by scholars (Bryant et al. 2001). However, the article identifies how Down syndrome is made absent in medical practice.

Risks, problems, and abnormalities

To recap, I offer three reasons why a discussion of Down syndrome is often avoided through absent or at least ambiguous engagements: the familiarity of the condition; the organization of care, and; the limited knowledge of professionals. So with the condition spoken around as opposed to spoken about, what existing (implicit) discourses shape Down syndrome within interactional exchanges? How is the condition discussed when, in turn, it is not discussed? The most common vernacular constructing Down syndrome, a vernacular infiltrating antenatal care and childbirth as a whole (Possamai-Inesedy 2006), is "risk"; expectant parents are provided with a "risk" factor, diagnostic testing carries a "risk" of miscarriage, older women are at an increased "risk" of having a child with Down syndrome, and so on. Discussions of risk in relation to prenatal screening/testing for Down syndrome are well-rehearsed in the literature (Thomas 2014; Heyman 2010; Markens et al. 1999). With regard to this study, the risk discourse is exemplified in the following consultation between Lois (midwife) and Mrs. Roberts (expectant mother):

Lois: This is just a chat about the Down syndrome test. Do you know much about Down syndrome screening?

Mrs. Roberts: Not really. I know if it's abnormal, they'll offer me another test.

Lois: Kind of. Do you know what Down syndrome is?

Mrs. Roberts: Yes.

Lois: OK. This is a screening test which won't affect the baby. You'll be placed in a higher risk or lower risk category. The test is 80% accurate so low risk does not mean no risk of having a baby with Down syndrome. If you're higher risk, we'll offer you an amniocentesis. The cut off is 1 in 150 so you could be 1 in 148, 1 in 149, 1 in 150, and all that is higher risk. So we offer the amniocentesis which takes fluid from around the baby and this says for definite whether your baby has an abnormality. But it does have a risk of miscarriage of 1% so if 1 in 100 women have the amniocentesis, one will miscarry. But what I badly need to know is whether you want to know whether you're a lower risk or higher risk.

Mrs. Roberts: Yes, just so I can know.

Lois: So you would consider having the amniocentesis?

Mrs. Roberts: I'm not sure. I'd have to speak to my partner.

Lois: But you'd like to know whether you're lower risk or higher risk?

Mrs. Roberts: Yes. I can do something about it afterwards then if something is wrong.

The consultation is described by Lois as "just a chat." This can be interpreted as an effort to manage Mrs. Roberts' anxiety. The absence of Down syndrome described earlier in the article, indeed, may also be viewed as professionals downplaying information until an actual diagnosis as a way of managing expectant parents' anxiety. However, an effect of describing the consultation in this way is that it implicitly and immediately downplays the significance of the event. Importantly, after Mrs.

Roberts confirms that she knows what Down syndrome is, no further details on the condition are offered. It retains its status as “abnormal,” an unchallenged label offered by Mrs. Roberts and one Lois later assumes. Lois recounts what she perceives as apt information for accomplishing appropriate care such as the accuracy of screening, risk factor cut-off rates, prospective diagnostic testing, and the risk of miscarriage. Notably, although diagnostic testing risks (e.g. miscarriage) are not explicitly outlined on the checklist discussed above, this is regularly mentioned in screening consultations with respect to point ten: “Have you considered the amniocentesis test that will be offered following a high chance result?”

During the consultation, Lois uses the word “risk” on several occasions. The implicit assumptions shaping wider readings of risk paint a negative picture. A potential risk status not only shifts health(y) identities of expectant mothers, but also demarcates Down syndrome itself as a “risk,” in effect, a threatening possibility. The widely-circulated term risk carries negative connotations; if something is a risk, it is to be feared and avoided (Lupton and Tulloch 2002). With risk indicative of a threat and having “connotations of danger and negative outcomes” (Shakespeare 1999:673), its common use within screening encounters portrays Down syndrome as a preventable pregnancy outcome. In addition, during the consultation between Lois and Mrs. Roberts, the offer of an amniocentesis “within 24 hours” not only highlights the gravity of the situation but also marks potentially detecting the condition as offsetting the possibility of miscarriage caused by diagnostic testing.

Interestingly, the use of the term risk was challenged by midwives and sonographers in both Freymarsh and Springtown and by governing bodies administering stipulations for best clinical practice. Members of each party suggest the term “chance” should be embraced over “risk” in consultations; expectant parents, for instance, should be told they receive a chance result, as opposed to a risk result, of having a child with Down syndrome (the checklist previously outlined in this article uses the term “chance”). Amy (midwife), among others, claims “risk sounds too negative.” However, observations reveal that whilst risk/chance was sometimes used synonymously by professionals, “risk” is used much more than “chance” in consultations. This oversight, highlighting the discrepancy between what one “says” and what one “does,” did not appear to emerge as a conscious decision. Rather, it is a product of the routinization and integration of a risk discourse in everyday practice, together with the observation that highly pressurized and medicalized service providers have yet to convert their language or thinking to reflect transformations in contemporary public culture and “official” legislative efforts which emphasize inclusion.

Within screening practices, the configuring of Down syndrome as a risk is reinforced with similar pervading classifications. At Freymarsh and Springtown, Down syndrome – since it is not cited explicitly – becomes synonymous with “problem,” “bad news,” “a bad scenario,” “something wrong,” and, most commonly, an “abnormality.” The fieldnotes taken during a nuchal translucency scan between Olivia (sonographer) and Mrs. Burton (expectant mother) highlight this:

Olivia: Now the nuchal translucency involves measuring the fluid at the back of the baby’s neck. This white line and this white line is where it is. We want that gap to be less than 3mm and I can say it looks tiny from first view.

Mrs. Burton: So that’s a good one?

Olivia: Yes.

Mrs. Burton: So it's a bad scenario if the bit at the back of the neck is not there then?

Olivia: No. The more it is, the higher the chance of abnormality. So a small measurement is good. The measurement is 1.6mm too which is brilliant.

Olivia repairs the impending danger of a "bad scenario" by highlighting the "brilliant" measurement which points toward the likely absence not of Down syndrome but of the much vaguer category of "abnormality." Despite the frequency of this repair work in consultations, a commitment to discursive categories of risks, problems, abnormalities, and bad scenarios – shaping Down syndrome as a universal "thing" – takes on greater significance once considering Francine's (midwife) suspicion that expectant parents "only really pick up keywords." Since professional conduct provokes interpretive acts among expectant parents, the discursive categories surrounding Down syndrome uphold it as a detrimental pregnancy outcome. Furthermore, it blurs the complexity of Down syndrome and the potential differences between two or more people with the condition.

It is true that Down syndrome is not a benign condition. Symptoms can be debilitating and, in some cases, fatal. However, the important point here is that the variability and complexity of the condition, namely as promising an uncertain prognosis yet often being "not lethal" (Ivry 2009), is masked by describing it in universal and negative terms which discount this complexity. This is also reflected in expectant parents being offered screening, at once, for several conditions and diseases including (but not limited to) rubella, HIV, syphilis, rhesus disease, sickle cell, thalassemia, hepatitis B/C, and Down syndrome. The positioning of Down syndrome, a condition categorized by many professionals as "compatible with life" and people with the condition as "good" human beings, with diseases/disorders such as HIV and hepatitis B/C demarcate and uphold it as one component of the (universal) abnormal category.

Discussion

In this article, I identify how an extensive discussion of Down syndrome is absent during screening consultations. I attribute this to three developments: 1) the familiarity of the condition to the British public; 2) the organization of care which renders a wider discussion of the condition as unnecessary and trivial; 3) the lack of knowledge among some professionals about Down syndrome. The condition is subsequently framed in the negative and universal categories of "risk," "problem," and "abnormality." In sum, I recognize how professionals can communicate, not communicate, or miscommunicate medical information as well as structural power arrangements, social knowledge, and ideas around certain bodies/future bodies (Rapp 2000).

The article offers three significant contributions to an anthropological understanding of reproduction. First, it highlights the pertinence of attending to absence and what/who is left off the table. Whilst a focus on interactional exchanges reveals what "is" said in the clinic, it also exposes what "is not" said, with the example of Down syndrome screening serving as a reminder of how absence has a social dimension which deserves and necessitates further reflection. What is left unsaid can be as important as, or more important than, what is said. Second, the article – in the tradition of Goffman (1959; 1963) and Garfinkel (1967) – highlights the value of analyzing the mundane, taken-for-granted components of everyday life and the ordinary routines deeply embedded in the fabric of medical

culture. The language of science and genetics claims to be neutral/universal yet it produces and reproduces rich, layered, and powerful messages (Rapp 2000; Rothman 1994). In this study, I do not rely on prescribed medical definitions of Down syndrome. Instead, I identify that by attending to banal discourses and practices, we can reveal how the condition is negatively constituted in mundane interactions and everyday medical work and talk.

Third, the article supports the call to deconstruct universalizing categories which trivialize and unfairly catalogue the social world into neat categories, thus discounting its intricacy and contradictions. Arguably, the medical work described here is not merely a trivialization or dismissal of the complexity of Down syndrome but, rather, a crucial example of exclusionary practices, at the mundane and implicit level, which stigmatizes certain ways of being in the world (i.e. having a disability). Down syndrome is a complex and heterogeneous condition, with symptoms varying significantly in each case, yet such inconsistencies in expression are rarely reflected in medical practice. The diversity in manifestation, together with better healthcare and education access for people with Down syndrome, seemingly contradicts medical descriptions of Down syndrome and the emphasis on prenatally detecting the condition, the latter observation being described by others as implicitly defining what kind of lives are worth living (Asch 1999; Press and Browner 1997). Although Down syndrome may be explained further by professionals once a diagnosis is established or largely suspected, the discourse around Down syndrome (as a risk, problem, and/or abnormality) in the early stages of antenatal care arguably shapes expectant parents' opinions and means that the damage may already have been done.

Healthcare professionals were the original driving force behind the introduction of innovations in prenatal diagnosis and, subsequently, screening (Vassy et al. 2014). In contemporary antenatal care, professionals are still located at the heart of screening practices, playing a key role in expectant parents' decision-making processes. Much of the debate around Down syndrome screening recurrently revolves around the discourse of choice, freedom, and neutrality/non-directive care, that is, an ideological framework described elsewhere as fiction (Asch 1999; Bosk 1992; Rapp 2000). This discourse legitimizes public policy (Vassy et al. 2014) yet frequently glosses over the need for a critical engagement with how Down syndrome and other conditions are configured (or not) in antenatal care. More broadly, it masks how the category of "abnormality" is both reproduced and expanded in such medicalized practices (Vailly 2008). Under the guise of giving pregnant women choice, developments in biomedicine allow for the control over the type/quality of fetuses (Vassy et al. 2014) and reproduce ideas around the "normal". In short, the categories of normality and abnormality are culturally constructed, associated with the production of a social, moral, and political order (Vailly 2008).

In relation to this study, I capture how Down syndrome – the condition itself and its complexity and variability – is both made absent (in line with public policy) and how it is implicitly condemned into the universal category of abnormal, that is, the opposite of normal, in antenatal care. I put forward that this portrayal emerges owing to these clinical practices, the routinization of "opt-in" screening in the context of no treatment (Down syndrome cannot be "cured/fixed" yet is the focus of prenatal detection), and the medicalization and technologization of biomedicine with its emphasis on developing "techniques capable of uncovering and managing deviants" (Vailly 2008:2541).

This article shows how Down syndrome and screening for the condition is entangled in political, social, and cultural debates in the realm of reproduction. Screening is a technology which both

enables and constrains, expanding opportunities whilst provoking dilemmas about the acceptability of intervention (Franklin 1997; Strathern 1992). Since screening practices so often spill beyond the biological and into public arenas and intimate lives alike, it is increasingly ripe for an anthropological analysis. With regards to this article, I suggest that by drawing attention to the mundane and everyday interactions of the antenatal clinic, we may uncover assumptions buried deep in medical culture. In addition, it identifies possible training needs for professionals such as improving current educational resources about conditions like Down syndrome, together with highlighting how requests to use the term "chance" instead of "risk" in consultations need to be fulfilled. In sum, this study – by offering "thick" descriptions of relatively "thin" encounters – reveals how Down syndrome is constructed in antenatal care and the implications this has when reflecting on the condition, and disability more generally, at the intersection of medical technologies. Since increasingly sophisticated prenatal technologies show no sign of abating, obstetric medicine will continue to transform and shape reproductive politics in Britain, as well as other countries offering screening, for the foreseeable future. It is within this context that the configuration, or absence/presence, of Down syndrome in clinical practice becomes of paramount importance for anthropologists of reproduction and for the people that prenatal technology directly implicates, namely, both expectant parents and healthcare professionals.

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Notes

1. A nuchal translucency is a collection of fluid in the nape of a fetus' neck. Screening for Down syndrome at Springtown involves measuring this fluid.
2. An "elephant in the room" is a British idiom for an obvious truth, risk, or problem which is overtly avoided or unaddressed.
3. Patau syndrome (Trisomy 13) and Edward's syndrome (Trisomy 18) are relatively rare chromosomal conditions categorized as incompatible with life.
4. There are three forms of Down syndrome: Trisomy 21 Down syndrome (94% of cases); mosaic Down syndrome (2% of cases), and; translocation Down syndrome (4% of cases). Only translocation Down syndrome can be hereditary.

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